

Health-related quality of life of family caregivers - evidence from Hesse

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Title page

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Health-related quality of life of family caregivers - Evidence from Hesse

Abstract

Aim:

The aim of the present study is to analyse the health-related quality of life (HRQOL) of primary family caregivers in comparison to the reference values of the average population.

Subject and Methods:

Data collection took place in the Werra-Meißner district in the year 2009 with a respondent rate of 102 primary family cares of frail elderly people. The health-related quality of life was measured with the Short Form 36 health survey (SF 36) and compared with the German reference values.

Results:

Compared to the health values of the normative sample, primary caregivers show significantly lower rates in all dimensions of the health-related quality of life. In particular caregivers between the age of 53 to 61 report extremely low health values. Caring women compared to noncaring women have highly significant differences in all subscales of the SF 36. Caregiving men as well report highly significant differences to noncaregiving men in all dimensions of the SF 36 except for Physical Functioning and General Health ($p<0.01$).

Caregivers in general and especially caregiving women in the age of 53 to 61 (midlife) were identified as at-risk groups for poor health. The latter report lower vitality and well-being which may be a consequence of both social isolation and social impacts from multiple - role demands.

Conclusion:

The identified high-risk groups of family carers, caregivers in midlife and especially caring women in midlife, should be strengthened by social support e.g. training courses for family carer particular in their home setting and various types of respite care in order to sustain their health.

Keywords

Family caregiver

health-related quality of life

SF 36

Gender differences

Introduction

In industrialised countries like the member states of the European Union, the life expectancy is increasing with an ascending average age. Although the additional years are supposed to be healthier than in earlier days (Schneider and Schwartz 2007), the number of elderly people in Germany living in need of long term care and assistance increases due to the steadily growing number of the very old.

The Federal Ministry of Health and Social Security (2003) (Bundesministerium für Gesundheit und Soziale Sicherung 2003) indicates an escalating risk to loose the ability to live independently with increasing age. While only 0.6 percent of the population under the age of 60 were in need of long-term care, the proportion of those between 60 and 80 years of age reached 4.3 percent in 2007. But approximately 31 percent of those above the age of 80 lived in need of long-term care and assistance in 2007 (see table 1).

Only persons who are complying with the nursing care levels according to paragraph 14 of the German Social Insurance Code (SGB XI) are registered in the statistical data. Estimated three million people who are in need of care are therefore not included according to lower levels of need in basic care (Schneekloth 2006).

+++insert Table 1+++

Table 1 Statistics of development of the population and dependency of care

The percentage of frail old people being cared for exclusively by family caregivers is 51.1 percent of all care recipients in nursing care level I, 32.9 percent in nursing care level II and 20.6 of all in nursing care level III.

786.000 of the 1.91 millions of care recipients aged over 60 years received exclusively nursing care allowance, so they completely relied on family caregivers. Further 467.000 persons received agency services and mixed benefits. 660.000 care recipients required institutional care (Statistisches Bundesamt 2009)

Already in 1995, Germany has implemented the public long-term care insurance (LTCI) as the fifth social insurance system. The expenditures of LTCI were rising from 4.97 billion Euros in 1995 to 18.34 in 2007 (a plus of 269.0 per cent). While the costs for nursing home care totalled 8.8 billion Euros in 2007, the expenditures on benefits for home care simply amount to 6.5 billion Euros with 2.5 billion Euros for agency care recipients and 4.0 billion Euros for family caregivers (Federal Statistical Office 2009).

Therefore, the family caregivers are an important pillar of the welfare and public health system in Germany. But the part of frail elderly people being cared for by their relatives is declining. The percentage of people in need of care being exclusively cared for by family caregivers has been decreasing to nearly 1 percent per year until 2005. Social and demographic reasons for this reduction are e.g. the downward trend in the birth rate, instable relationships, higher rates of divorce leading to more single households and lower rates of daughters-in-law (Döhner and Rothgang 2006; Haberkern and Szydlik 2008), as mainly wives, daughters or daughters-in-law were responsible for caring their relatives.

However 83 percent of the family caregivers felt severely burdened with their role, while 12 percent did not feel burdened and only 5 percent did not even feel strained (Schneekloth 2006). The aim of the present paper therefore is to analyse whether caregivers in Germany can be pronounced healthy to keep going on with their caregiver role.

Background

To care for a frail, ill or disabled family member integrates various activities in basic care and assistance. Often caregiving behaviour is conceptualised in terms of specific tasks (Abel 1990). Care recipients who are limited in routine personal activities of daily living (ADL) need assistance with personal hygiene, eating, toilet use or excretion and mobility. Therefore, family caregivers provide a wide range of personal care tasks such as washing, showering, bathing, dental hygiene, hair combing and shaving. Furthermore, they help with eating and preparing food bite-sized, give assistance with toileting or supply support in case of inability to control urination or defecation. Additionally, caregivers help with dressing and undressing, getting the care recipients in or out bed and assist with moving or transferring. The caregiving literature shows a number of assessment instruments to comprehend the functional limitations and to measure the physical disability of the care recipients. The Activities of Daily Living Scale (Katz et al. 1963) and as well the Barthel ADL Index (Mahoney and Barthel 1965) were developed to describe and visualise the individual progress of physical health effects after hip fracture or in the general context of physical rehabilitation. However, in Germany mainly the ADL scales were used as a basis to define the public guidelines of the statutory long-term care insurance (Bartholomeyczik 2007).

Moreover, frail old relatives in need of care are unable to conduct instrumental activities of daily living (IADL). Therefore, family caregivers have to support their family members with instrumental tasks such as doing housework, cooking, doing laundry, heating the home, grocery shopping, transporting, managing finances, and administering medicine. Assessment instruments to measure the amount of IADL are e. g. the Instrumental Activities of Daily Living Scale (Lawton and Brody 1969) or the modified version of the Older Americans Resources and Services (OARS), a Multidimensional Functional Assessment Questionnaire that measures both ADL and IADL (Fillenbaum and Smyer 1981).

However, caring for a relative as well influences emotional dimensions of the kinship. Due to the care recipient's dependency on the family caregiver's permanent help, the reciprocity within the relationship of this two involved family members is increasing (Pearlin et al. 1990) what may even lead to role reversal (Cantor 1983).

Providing care for a frail elderly person is supposed to cause considerable burden and increased stress to family caregivers (Zarit et al. 1986; Gräbel 1998; Burton et al. 2003). The experienced strain due to the caregiving situation is said to lead to physical, emotional and mental exhaustion and sometimes even to burnout (Almberg et al. 1997; Wilz et al. 2005; Eith et al. 2010).

Although burden has been one of the most frequently studied topics in the family caregiving literature between the 1970s and 1990s (Jeon 2003), there is no consistent definition or measurement of burden. Within a theoretical framework, mainly stress and coping theories are used which describe burden as a situation specific, multidimensional construct (George and Gwyther 1986; Pearlin et al. 1990), with a central aspect of distinction between subjective and objective burden (Vitaliano et al. 2003). Subjective and objective burden might have negative effects on the psychological and physical health of the family caregivers.

There is a comprehensive literature on the impact of caregiving on mental health and well-being (Schulz et al. 1995a). Especially caring for relatives with behaviour problems and dementia can lead to higher levels of depression (Baumgarten et al. 1992) and adversely affect psychological morbidity (Gilhooly and Sweeting 1994; Gräbel 1998).

Caregiving women usually tended to complain higher levels of subjective and objective burden than caring men (Chang and White-Means 1991) and reported greater psychiatric morbidity attributable to caregiving (Yee and Schulz 2000) and lower mental well-being (Pinquart and Sörensen 2006).

Caregiving tasks involving personal care and bodily contact correlated with higher levels of perceived burden (Montgomery et al. 1985). Living together and sharing the same household led to the highest levels of stress (Cantor 1992) and lowest level of well-being (George and Gwyther 1986).

However the experience of continual psychological and physical demands of caregiving may as well affect the physical functioning and physical health of the family caregivers (Schulz and Beach 1999), (Pinquart and Sörensen 2003), although the feeling of being depressed may be stronger associated to worse physical health than caregiving demands (Pinquart and Sörensen 2007).

Poorer self-related physical health of primary caregivers was found in several studies subject to characteristics of the caregiving context e.g. coresidence with the care recipient (Pinquart and Sorensen 2007), prolonged duration of the caregiver role (Matthews et al. 2004), more hours of care per week (Navaie-Waliser et al. 2002), being a spousal caregiver (Barnes et al. 1992), advanced age of the caregiver (Strawbridge et al. 1997), lower socioeconomic status (Hughes et al. 1999), lower levels of social support (Goode et al. 1998) and the severity of the care recipients behaviour problems and cognitive impairment (Schulz et al. 1995b).

Objective health measures like stress, hormones, or antibodies were found to be of 23 per cent higher level of stress hormones and 15 per cent poorer antibody production (Vitaliano et al. 2003) as well as significantly higher levels of systolic and diastolic blood pressure (Kim and Schulz 2008) for caregivers compared to noncaregivers.

But findings are heterogeneous and not unambiguous. However some researchers emphasized a positive outcome to family carers (Kramer 1997). The responsibility for the care recipient led to personal growth (Leipold et al. 2006) and provided intrinsic rewards as experienced self-gain of the caregivers (Foley et al. 2002). In addition, one recently run study in the United States of America indicated that the caring for a disabled spouse more than 14 hours a week may even lead to an increased life expectancy (Brown et al. 2009).

To measure self-reported health with several validated assessment instruments has achieved an increasing acceptance in medicine (Bullinger 2000). Sensitive measurement tools to identify health differences in a general population use as an outcome variable the health-related quality of life (HRQOL), which measures both the self-perceived mental and physical health.

Various studies on the effects of caring with respect to demographic characteristics of the caregiver and care recipient and their relationship interrelate and influence the health-related quality of life, led to heterogeneous findings.

Comparing an American caregivers sample with the average U.S. population the caregivers showed stronger association of mental functioning than physical functioning with caregiving by using the SF-12 Mental and Physical Component Summary scores (Markowitz et al. 2003). The weekly hours of caregiving were related to lower mental functioning of the caregiver, while better mental health values were received by male caregivers, spousal carers and older caregivers. Only younger caregivers showed poorer physical functioning than population normative values of the same age.

A study about Japanese caregivers measuring HRQOL with the SF-36 indicated a stronger association between feelings of burden with mental health than physical health (Miura et al. 2005).

The HRQOL of primary Taiwanese caregivers were compared to the normal Taiwanese population with the results that caregivers reported better physical health values than the general population but had a worsened status in mental health (Li et al. 2004).

Studies of the situation in Germany are rare, and they by and large analyse interventions with dementia caregivers (e.g. Donath et al. 2009; Schacke and Zank 1998) and not with family caregivers in general.

But the health status of the caregivers is an important predisposing factor for the transition from home care to institutionalization of the care recipient (Deimling and Poulshock 1985).

Therefore, it is necessary to get detailed information focusing the problem whether and to which respects family caregivers differ from the average German population regarding health – related quality of life. Based on empirical data the following questions will be examined:

Does the health-related quality of life of family caregivers differ significant from the average population regarding the data from the German normative sample of life?

Are there significant health differences according to gender and age by comparing the German normative sample and the family carers?

Which dimensions of the health-related quality are significantly different between caregivers and noncaregivers?

Methods

Family caregivers' health-related quality of life was measured with the questionnaire Short Form-36 Health Survey. This generic instrument was developed as a short form of the instruments used in the Medical Outcome Study (MOS) and is now used in clinical practice and research, health policy evaluations, epidemiologic studies and general population surveys (Ware and Sherbourne 1992). The SF-36 is a morbidity assessment measuring a profile of eight dimensions with a varying number of items: Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE) and Mental Health (MH) (Bullinger 2000; Ellert and Kurth 2004).

The Physical Functioning subscale contains 10 questions and indicates the extent to which the state of health limits the performing of physical activities such as basic activities like bathing or dressing as well as moderate and vigorous activities. The Physical Role Functioning subscale measures with four questions the extent to which the physical state of health is interfering with work or daily activities. The Bodily Pain subscale with two questions shows the extent to which daily activities interfere with pain and the influence of pain. The dimension General Health consists of five questions and contains the self-reported health status, including the current state of health perception and future prospects. Vitality with four questions as the fifth dimension shows how people feel as to dynamics and energy. The subscale Social Functioning with two questions indicates the extent to which the state of health or emotional problems limits the performing of social activities. The subscale Role-Emotional with three questions measures the extent to which emotional problems are interfering with work or daily activities. Mental Health consists of five questions and describes the general mental health including depression, anxiety, emotional and behaviour-related control as well as general positive mood (Bullinger and Kirchberger 1998).

For the five subscales Physical Functioning, Role-Physical, Bodily Pain, Social Functioning and Role-Emotional the responses are combined to generate a score from 0-100, where the score of 100 indicates best health without any limitations or disabilities. The subscales General Health, Vitality and Mental Health are bipolar and a score in the mid-range shows no limitation or disability, while a score of 100 can only be received if respondents report positive states (Hughes et al. 1999).

Furthermore the higher-order summary scores: Physical Component Summary (PCS) and Mental Component Summary (MCS) (Ware, JR. et al. 1995) were calculated to compare these scores to the average German Population. The PCS is computed by placing greater weight on the subscales Physical Functioning, Bodily Pain, General Health and Role Physical. Also PCS score has a range from 0 to 100 with lower scores showing greater level of impairment (Badr et al. 2007).

The German normative population sample from the German Nation Health Interview and Examination Survey 1998 (Ellert and Kurth 2004) utilised the Short Form 36-Questionnaire to measure the health-related quality of life.

Due to methodical reasons, as different illness prevalence, only the data of the German normative population belonging to the formerly western part of Germany were included. For further comparison the dataset was extracted and only the same age-structure as found for family cares with people aged from 25 to 84 years was included. These remaining data were compared with the values of the family caregivers by using statistical analysis.

Results

Data was collected in the Werra-Meißner district in the north of Hesse (Germany) between November 2008 and June 2009. The Werra-Meißner district is one of the counties in Germany with the highest rate of elderly people living in need of long term care and assistance.

564 questionnaires were handed out to primary family caregivers by family physicians, ambulatory care services and suppliers of medical devices. 114 completed questionnaires have been received back, a correspondent rate of 20.2 percent. A total of 102 caregivers meet the inclusion criteria: being the primary caregiver, caring at least more than one year for a care recipient aged about 61, eligible within the LCTI levels.

The identified demographic characteristics of the family caregivers contain age, gender, relationship to the care recipient, occupational status of the caregiver, nursing care level, residence and income. The details are as follows:

The caregivers' age ranges from 25 - 84 years with a mean age of 57.1 years. The average age of the care recipients is 79.1 years with a range from 61 to 96. The mean duration of the years of caregiving amounts to 4.3 years (SD 3.5 years). The daily hours of caregiving tasks are 9.7 hours (SD 8.2).

The majority of the caregivers are women (72.5 %). 79.4 percent of the caregivers are married or live in a partnership. The occupational status shows that 35.3 percent of the caregivers have jobs in addition to providing care, 34.1 percent are already retired and 31.8 percent are not employed.

While 26.5 percent of the caregivers are spouses of the care recipients, 61.7 percent are daughters and daughters-in-law. 40.2 % of the caregivers care for their mother, 8.8 % for their father and 12.7 % for their mother-in-law, but none care for their father in law.

Within the group of female caregivers 21.6 percent cared for their spouse, 51.3 percent for a parent and 17.6 percent for a mother in law.

42.9 percent of the male caregivers cared for a spouse and also 42.9 percent cared for a parent. None of the male caregivers cared for a mother in law.

68.6 percent share the household with the care recipient. 33.3 percent of the care recipients are classified as care level 1, 40.2 percent as care level 2 and 26.5 percent represent care level 3 (see table 2).

+++insert Table 2+++

Table 2 Overview of the characteristics of the caregiver sample

Statistical analysis of the data was calculated with SPSS ©, version 15.0.

For all eight subscales of the SF-36 the reliability measured by Cronbach's alpha ranges from .784 to .946.

As the values of the SF-36 are not normally distributed, Mann-Whitney-U-tests have been conducted to compare the health variables of the normative sample and the family carers.

The results indicate that the family caregivers perform high significantly lower values (p<0.0001) in all eight dimensions as well as in both summary scores PCS and MCS (see table 3).

+++insert Table 3+++

Table 3 Comparison of the values normative sample and family carer

By contrast with analysing different age clusters, slightly divergent results are found (see Table 4). Therefore the sample is divided into three different age groups as group 1, with the age from 25 to 52 years, group 2 with the age from 53 to 61 years and group 3 with the age from 62 to 84 years. The age group from 25 to 52 shows high significant differences in six subscales and MCS ($p<0.001$), but the differences in the dimensions Physical Functioning and General Health as well as PCS are only significant at the 0.01 level.

The health values of the caregivers 53 to 61 years rank lowest with high significant results ($p<0.001$) in all dimensions with the exception of the Physical Functioning ($p<0.05$) and PCS ($p<0.01$). 86 percent of this age group is married and 13.9 percent is caring for a spouse or partner. While 83.3 percent are caring for a parent or a mother-in-law. Just 3 caregivers have no children (mean age of the first child 33.7 years) and 41.5 percent of the caregivers have an additional job. But the comparison of nonworking and working family carers does not show significant results. 58 percent of this age-group is sharing one household with the care recipient. But the health values of those who live in one household with the care recipient do not differ significantly in any subscale from those who do not live in coresidence with the one they care for.

In the third age group, high significance only exists in the dimensions Social Functioning, Role-Emotional and Mental Health ($p<0.001$). The Mental Health Summary score is high significant as well ($p<0.001$). Role-Physical and Vitality are just significant ($p<0.01$). Bodily Pain is just significant at the 0.05 level.

No significance is found for Physical Functioning, General Health and PCS. Within the sample of this age group 90 percent are married, 64 percent are caring for a spouse or partner and nearly all of the caregivers have retired (except 2 cases). Just 3 caregivers had no children (mean age of the first child 44.9 years) and the majority, 28 cases (84.8 percent), shared one household with the care recipient.

+++ insert Table 4 +++
Table 4 Health values regarding different age cohorts of average population versus caregivers

Further Mann-Whitney-U-tests are used to analyse whether gender differences influence the health values. Significant differences ($p<0.001$) are found between women of the normative sample and female caregivers. Also within the two groups of male caregivers and the average male population the results show high significance except for Physical Functioning and General Health perception ($p<0.01$). Caregiving women show significantly higher PCS and MCS than the average female population, caregiving men differ high significantly in MCS, while the difference in PCS is just significant ($p<0.05$) to the average male population (see table 5).

+++ insert Table 5 +++
Table 5 Comparison of health values for noncaregiving and caregiving women and men

To take a closer view on the gender differences, the health values of the normative sample and the population are compared with Mann-Whitney-U-tests. The values of women and men within the normative sample differ high significantly in seven dimensions except for the General Health subscale ($p<0.01$) while the family caregivers show no significant differences according to gender (see table 6).

+++ insert Table 6 +++
Table 6 Comparison of gender differences within the health values

Discussion

The prevalent opinion that caregiving affects the health of family caregivers was confirmed in the present study. In all eight dimensions of the self-related health as well as in the two summary scores MCS and PCS the family caregivers showed highly significantly lower values ($p < 0.0001$) than the average population in Germany.

The caregivers report limitation in daily and social activities. The differences to the normative sample for these subscales and for Mental Health stayed highly significant also within the three different age cohorts.

The oldest age cohort showed no significant difference for Physical Functioning, General Health and the PCS. The subscales Bodily Pain and Role-Physical varied significantly ($p < 0.05$ and $p < 0.01$). The age group from 62 to 84 years showed in comparison to its age cohort of the normative sample the best health values.

It might be concluded that only healthy older people can cope with the demands of the caregiver role and therefore older relatives who already are in poor health will not become caregivers. However, this age-group is not involved in other demanding and inflexible roles like employment or supporting children. Furthermore in this period of the life-span, persons who are cared for usually are spouses or partners of the caregivers. This might reinforce the impression that “this is just the time to care” and caregiving becomes an accepted life concept.

The age group between 53 and 61 years reported absolutely and relatively exceedingly poor health values in relation to the reference values and in absolute terms. Within all seven subscales except for Physical Functioning the health values differed highly compared to the normative group. In total the averages were even lower as those of the oldest age cohort. Therefore an incremental age related correlation of health values could not be confirmed for all dimensions of the health-related quality of life for family caregivers.

Young and middle-aged caregivers tend to experience more subjective burden maybe because they are involved in other competing social roles, which are competing and demanding like supporting young-adult children (Lee and Gramotnev 2007) or living in a partner-ship or inflexible and demanding like employment.

That midlife caregiver reported higher levels of depression than the older age-cohorts when caring for dementia care recipients was already confirmed by Covinsky et al. (2003). It may be due to an abrupt transition into retirement caused by circumstances beyond their own control that women report lower levels of well-being (Szinovacz and Davey 2004). Both findings can be summed up as the results of social isolation.

Within the German normative sample gender differences were highly significant. Women described a lower evaluation of health-related quality of life (Bullinger 2000). This result did not apply to the sample of family caregivers. Although the health values tended to be lower for women, the differences were not significant. The same effect was found in all clinical populations, e.g. patients with chronic pain, migraineurs, high blood pressure patients, patients with artery occlusive disease or back pain patients (Bullinger et al. 1995). Hence maybe a bold conclusion could be drawn, that family caregivers could be as well regarded as a group of clinical population.

Comparing the health values of caregiving men and the comparing data of the normative sample, the results showed significance for General Health and Physical Functioning. But looking at the health values of caregiving women and the normative data of women all subscales showed high significant results. This could be explained by the fact that women reported poorer values of Physical and General Health. But gender differences in health perception require a closer multidimensional examination. In industrialized countries women tend to report poorer health than men. So already Blaxter (1990) noted: “At all ages women experienced, or are more ready to describe, more illness and higher rates of psychosocial malaise than men. This is, of course, an invariable finding in health surveys.” The self-report of health complaints is mainly influenced by the self-concept. Sieverding (2005) indicated that men do not admit to suffer from poor health conditions which might be caused by the traditional ideal of masculinity.

Within the rural Werra-Meißner-district there may exist a traditional pre-modern conception of life, where the ideal to care for their relatives is socially honoured but with fixed role expectations. This might influence the fact that caregiving men are still underrepresented. But for the future also men need to be more integrated into family caregiving.

Although the rate of respondents was just 20.2 percent this is a common result within a sample of family caregivers. Often the method of the non-random recruited samples as used in this study are criticised resulting in higher amount of perceived burden (Sörensen et al. 2002; Pruchno et al. 2008), the reported values are comparable to a great number of findings within family caregiver investigations.

Being aware that these results have limitations and do not picture totally the general situation all over Germany they are reliable to give detailed and conclusion nouns and hints to deal with the central aspects of modern individualised societies.

Conclusion

As Sato (2009) could show in a comparison of all 16 states in Germany by using data of the Federal Statistic Office, regions with a high income and a small number of unemployed people prefer nursing home care. The state Hesse ranked low on nursing home care as well as in using home care services. So in this rural area the family carers are the backbone of the LTCI.

The identified at-risk groups of family carers, caregivers in midlife and especially caring women in midlife should be strengthened to cope with the demands of providing care. Caregiver and especially women in midlife were identified as at-risk groups for poor health. The reported lower vitality and well-being may be due to both social isolation and social impacts from multiple - role responsibilities and demands.

Social support for family caregivers of elderly people, whether it is received from institutions or from private social networks, is regarded as a possible coping resource, which may buffer emotional strain and burden within critical life-events and affects mental well-being (for an overview Sörensen et al. 2002; Stoltz et al. 2004; Smeglia et al. 2007; Stummer 2007). Family carers who reported low values of satisfaction with social support had significantly poorer health and well-being than the carers who manifest high values of satisfaction with social support (Rösler-Schidlack et al. 2010), be it from the private social network, from governmental institutions (Beyweiss and Ostermann, 2009) or the development of long-term nursing networks (Ostermann et al. 2009).

According to the above mentioned study results and other investigations the necessity for strengthening the situation of caregivers is evident. But the financial consequences could be enormous. The German public health is scrutinised at the moment by many investigations. It is doubted that the total amount for it could be expended. Therefore decisions have to be taken which significance should be given to the situation of the caregivers.

In July 2008 Germany has extent the LTCI with the Long-term Care Further Development Act. Nearly all kind of benefit amounts will be slightly raised until 2012.

Our results, the measured poor health-related quality of life of family caregivers and especially the inadequate physical and general health of the caregiving-women, show the existing need to get a relief of the strain of family care. Thereto different kind of measures such as instrumental support and information on caregiving tasks should be combined with health-promoting interventions and respite for family caregivers.

In particular, better and more access to attendant care for heavy caregiving tasks as well as courses of instruction in providing care may help to reduce the physical burden of the female caregivers.

Training courses for family carers are statutorily regulated (§ 45 SGB XI). They are free of charge and may even be carried out at the care-recipients' home but are still underutilised (Lamura et al. 2006)

and rather used if the burden is still low (Schneekloth and Wahl (ed.) 2005). Training courses have positive effects on the well-being and the quality of life of the family carers especially if they include caregiving qualifications as well as bodywork for the caregiver such as relaxation techniques and training of self-perception (Dörpinghaus 2006). Therefore the care funds should actually realise these courses in the home setting of the family caregivers particular in rural destinations so that more caregivers can take part.

Professional instrumental support, as attendant care by out-patient care services can be received as benefits in kind. But the costs of repeated daily attendance of nursing help are not totally covered and an additional payment may exceed some families' means. A new form of combining entitlements to benefits in kind for several persons in need of care living near together, the so-called "pooling" (§ 36 (1) SGB XI), may improve the efficiency so that more family caregivers are likely to participate.

Referring to respite care, the care funds pay for the substitution of the family carer in case of holiday or illness up to an amount of € 1.510 and a maximum of 28 days a year for short-term care in a nursing home or home care provided by another person or out-patient care services (§ 39 SGB XI). Also semi-residential care as monthly benefits in kind for care in day and night centres is available with different grants according to the care level category. If the use of respite care is less than eight hours a day in the own home, part time respite care can be utilised up to an amount of € 1.510 per year (Spitzenverbände der Pflegekassen 2008). Thereto low-threshold care services or other volunteers can be incorporated.

Currently the utilisation of respite care is still modest. This is mainly due to additional high costs and lacking information (Döhner and Rothgang 2006) or to reservations leaving the care-recipient alone (Gräbel 1998). Particularly women are regarding family care as a personal problem owing to social norms (Cossette et al. 1995). The availability and offers of affordable low-threshold care services may help to change this social attitude.

New infrastructure as [Community Care Access Centers long-term care support bases \(for an overview e. g. Klie and Monzer 2008; Schaeffer and Kuhlmei 2008; Pflegestützpunkte\)](#) provides the opportunity to combine care counselling with the integration of various social welfare agencies and the activities of volunteers. Care-recipients and their relatives got the statutory right to get professional advice from case managers. Those caregivers, who exclusively receive cash benefits without any help by out-patient care services, are obligated to individual care consultations twice a year within care level I and II and four times a year within care level III (§ 37 SGB XI). The case managers should be sensitised to pay attention to the health status of the family carers and strengthen especially burdened women to utilise health prevention measures and rehabilitation.

Furthermore family caregivers got the right to leave their job for a period of six month unpaid with a guaranteed return. Whether the above identified at-risk group for poor health the middle-aged family caregivers can extract health advantages from this measure should be closely observed in further investigations.

Conflict of interest

The authors declare that they have no conflict of interest.

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	1999	2001	2003	2005	2007
German population (total)	82.163.475	82.440.309	82.531.671	82.437.995	82.217.830
Population, aged 60-80	15.939.714	16.652.942	16.918.993	16.899.789	16.854.655
in need of care, aged 60-80	687.209	678.786	683.803	690.007	716.738
<i>percentage in age group</i>	<i>4,3</i>	<i>4,1</i>	<i>4,0</i>	<i>4,1</i>	<i>4,3</i>
Population aged over 80	2.957.885	3.215.172	3.466.330	3.709.710	3.946.456
in need of care, aged over 80	1.014.590	1.058.614	1.091.872	1.135.444	1.214.099
<i>percentage in age group</i>	<i>34,3</i>	<i>32,9</i>	<i>31,5</i>	<i>30,6</i>	<i>30,8</i>
Population aged over 60	18.897.599	19.868.114	20.385.323	20.609.499	20.801.111
in need of care, aged over 60	1.701.799	1.737.400	1.775.675	1.825.451	1.930.837
<i>percentage in age group</i>	<i>9,0</i>	<i>8,7</i>	<i>8,7</i>	<i>8,9</i>	<i>9,3</i>
<i>percentage entire population</i>	<i>2,0</i>	<i>2,1</i>	<i>2,2</i>	<i>2,2</i>	<i>2,3</i>

Own calculation with data from Federal Statistical Office (2009)

Table 1 Statistics of development of the population and dependency of care

(values of whole sample in brackets)	Female caregiver n = 74	Male caregiver n = 28
Caregivers age (57.14, SD 12.15)	56.0 (SD 11.0)	60.01 (SD 14.47)
Duration of caregiving in years (4.3, SD 3.5)	4.3 (SD 3.5)	4.05 (SD 3.5)
Daily hours of caregiving (9.7, SD 8.2)	9.8 (SD 8.3)	9.3 (SD 8.3)
Living together with the care recipient (68.6 %)	68.9 %	67.9 %
Assignment within the German care level scale		
Care Level 1 (33.3 %)	32.4 %	35.7 %
Care Level 2 (40.2 %)	41.9 %	35.7 %
Care Level 3 (26.5 %)	25.7 %	28.6 %
Carer-elder relationship		
Partner or spouse (26.5 %)	21.6 %	42.9 % 12 cases
Parents (49.0 %)	51.3 % mother 30 cases father 8 cases	42.9 % mother 11 cases father 1 case
Mother or father in law (total 12.7 %)	17.6 % (mother in law)	none
Other relationship (uncle, aunt, siblings) (11.8 %)	9.5 %	14.3 %
Caregiver occupational status		
Working (36.3%)	40.5 %	25.0 %
Retired (34.3 %)	25.7 %	57.1 %
All other non-working (29.4 %)	33.8 %	17.9 %
Caregiver material status		
Married or living with a partner (79.4 %)	85.1 %	64.3 %

Table 2 Overview of the characteristics of the caregiver sample

SF-36 Scales	Normative sample n=1719 Mean (SD)	family carer (FC) n=102	difference	reliability	significance
Physical Functioning	84.0 (23.5)	73.3 (26.5)	-10.7	.946	.000***
Role-Physical	81.2 (34.1)	52.7 (39.0)	-28.4	.800	.000***
Bodily Pain	77.6 (28.3)	57.8 (25.7)	-19.8	.880	.000***
General Health	65.6 (20.4)	52.2 (21.0)	-13.4	.784	.000***
Vitality	61.6 (18.9)	43.1 (19.6)	-18.5	.859	.000***
Social Functioning	87.4 (19.9)	56.6 (25.8)	-30.8	.832	.000***
Role-Emotional	89.1 (27.4)	53.5 (41.7)	-35.7	.808	.000***
Mental Health	73.1 (17.0)	56.3 (20.0)	-16.8	.879	.000***
Physical Component Summary	49.2 (10.7)	44.4 (12.1)	-4.9	-	.000***
Mental Component Summary	51.5 (8.5)	38.9 (9.8)	-12.2	-	.000***

***p<0.0001

Table 3 Comparison of the values normative sample and family carer

SF-36- subscales	age structure 25-52 years		age structure 53-61 years		age structure 62-84 years	
	normative sample n=982	family carers n=33	normative sample n=270	family carers n=36	normative sample n=467	family carers n=33
Physical Functioning	92.02	85.00**	84.19	72.38*	67.03	62.34
Role-Physical	87.85	60.61***	79.63	47.92***	68.01	50.00**
Bodily Pain	83.71	65.94***	75.04	50.53***	66.96	57.66*
General Health	71.34	60.44**	61.70	45.03***	55.91	52.90
Vitality	64.11	49.38***	61.75	36.71***	56.07	43.70**
Social Functioning	88.90	55.30***	88.06	49.65***	83.88	65.53***
Role-Emotional	90.03	58.59***	90.92	47.22***	86.24	55.21***
Mental Health	73.49	60.75***	73.29	52.47***	71.99	55.92***
Physical Component Summary	52.81	48.9**	48.1	42.5**	42.27	41.8
Mental Component Summary	50.52	39.8***	51.6	35.9***	52.1	41.3***

* p<0.05 **p<0.01 ***p<0.001

Table 4 Health values regarding different age cohorts of average population versus caregivers

SF-36-Scale	normative sample women n=935	female caregivers n=74	normative sample men n= 784	male caregivers n=28
Physical Functioning	81.74 (24.68)	71.38 (27.75)***	86.65 (21.77)	78.39 (22.61)**
Role-Physical	78.20 (35.88)	51.71 (39.82)***	84.67 (31.43)	55.36 (37.49)***
Bodily Pain	75.17 (29.15)	56.82 (24.40)***	80.45 (27.04)	60.46 (29.09)***
General Health	64.66 (20.51)	51.53 (20.57)***	66.80 (20.20)	54.00 (22.22)**
Vitality	58.88 (19.15)	42.30 (19.49)***	64.80 (18.01)	45.00 (20.18)***
Social Functioning	85.47 (21.50)	56.25 (26.03)***	89.72 (17.67)	57.59 (25.76)***
Role-Emotional	86.91 (29.52)	52.05 (41.94)***	91.81 (24.31)	57.14 (41.43)***
Mental Health	70.39 (17.72)	56.02 (19.35)***	76.25 (15.42)	57.00 (21.74)***
Physical Component Summary	48.5 (11.1)	44.0 (9.5)***	50.1 (10.1)	45.4 (10.6)*
Mental Component Summary	50.0 (9.1)	38.7 (12.0)***	52.4 (7.5)	39.4 (12.5)***

*p<0.05 **p<0.01 ***p<0.0001

Table 5 Comparison of health values for noncaregiving and caregiving women and men

SF-36 Scales	German normative sample			Family caregiver		
	total n=1719	men n=784	women n=935	total n = 102	men n= 28	women n=74
Physical Functioning	83,99	86,65	81,74***	73,32	78.39	71.38
Role-Physical	81,15	84,67	78,20***	52,72	55.36	51.71
Bodily Pain	77,58	80,45	75,17***	57,82	60.46	56.82
General Health	65,64	66,80	64,66**	52,22	54.00	51.53
Vitality	61,57	64,80	58,88***	43,06	45.00	42.30
Social Functioning	87,41	89,72	85,47***	56,61	57.59	56.25
Role-Emotional	89,14	91,81	86,91***	53,46	57.14	52.05
Mental Health	73,06	76,25	70,39***	56,29	57.00	56.02

*p<0.05 **p<0.01 ***p<0.001

Table 6 Comparison of gender differences within the health values